American College of Medical Genetics
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American College of Medical Genetics Affirms Importance of Newborn Screening (NBS) Dried Blood Spots in New Position Statement: *National Public Health Officials and NBS Experts Also Show Support of Position*

BETHESDA, MD – May 6, 2009 | The American College of Medical Genetics (ACMG) has issued a new Position Statement on the Importance of Residual Newborn Screening Dried Blood Spots. In May 2006, the American College of Medical Genetics recommended that all newborns in the United States be uniformly screened for 29 conditions. Tremendous progress has been made in implementing broader and more consistent newborn screening since then and it is estimated that thousands of babies' lives have been saved or have been spared from serious disease as a result of the expanded NBS. A critical aspect of newborn screening is the "dried blood spot, filter card" which provides the specimen on which the screening is done. The left-over sample is useful in follow-up testing and other uses aimed at ensuring high quality newborn screening in the United States.

"Residual dried blood spots are vital to effective newborn screening across the United States," said Michael S. Watson, PhD, FACMG, Executive Director of the American College of Medical Genetics. "There has been some debate recently whether the residual dried blood spots should be destroyed after screening and the ACMG has released this statement to convey accurate information about the use of the residual dried blood spots as well as to reinforce the value of the residual spots for their use in improving newborn screening and child health." The Position Statement affirms:

- Residual newborn screening dried blood filter spots are a valuable national resource that can contribute significantly to the health of our children.
- Newborn screening blood spots are stored with rigorous control and respect for privacy and confidentiality to protect the public.
- If a state decides that newborn screening blood spots should not be retained or used for anything more than the screening test, it is critical that individuals have the option of having their children's dried blood spots deposited in a national repository which will allow for necessary studies under appropriate privacy and confidentiality protections.

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Statement of Support from Newborn Screening, Consumer Advocacy and Public Health Officials:
On April 6-7, 2009, the Regional Genetics and Newborn Screening Collaboratives' National Coordinating Center (NCC) convened a meeting, which was jointly funded by HRSA MCHB/GSB and the Eunice Kennedy Shriver NICHD, to discuss state newborn screening programs with regard to the goals of the Newborn Screening Saves Lives Act (PL 110-204). Meeting attendees included representatives from state NBS programs, state screening laboratories, state legal representatives, academic institutions, consumer advocacy organizations and the relevant large federal agencies as well as clinicians. The following statement was developed and agreed upon regarding the extremely high value of residual blood spots while also balancing public good with research interests and maintaining privacy and confidentiality as a central focus.

"Newborn screening (NBS) is a valuable public health prevention activity that continuously evolves to improve and optimize the health of our children. One product of the multi-faceted NBS process, the residual dried blood spots (DBS), serves as an additional valuable resource, whose benefits were discussed at length. Their overall use includes facilitating the improvement and evolution of newborn screening programs nationwide. It is envisioned that their uses will improve and change as scientific advances occur in the coming years. It is the desire of the group to encourage these developments with the continuation of appropriate stewardship to assure privacy and confidentiality.

Meeting attendees agreed that moving forward policy needs to recognize the three classes of residual DBS use. These include: 1) improvement of current screening programs; 2) introduction of new screening tests; and 3) expanding medical knowledge related to NBS."

Visit www.acmg.net for the Position Statement on the Importance of Residual Newborn Screening Dried Blood Spots.

About the American College of Medical Genetics
Founded in 1991, the American College of Medical Genetics (www.acmg.net) advances the practice of medical genetics by providing education, resources and a voice for more than 1400 biochemical, clinical, cytogenetic, medical and molecular geneticists, genetic counselors and other healthcare professionals committed to the practice of medical genetics. ACMG's activities include the development of laboratory and practice standards and guidelines, advocating for quality genetic services in healthcare and in public health, and promoting the development of methods to diagnose, treat and prevent genetic disease. *Genetics in Medicine*, published monthly, is the official ACMG peer-reviewed journal. ACMG's website (www.acmg.net) offers a variety of resources including Policy Statements, Practice Guidelines, Educational Tools, and a Medical Geneticist Locator. The educational and public health programs of the American College of Medical Genetics are dependent upon grants, contracts and charitable gifts from corporations, foundations, and individuals. The **American College of Medical Genetics Foundation** (www.acmgfoundation.org) is a 501(c)(3) not-for-profit organization dedicated to funding the College's diverse efforts to translate genetic discoveries into health practices.

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